

# Developing a Comprehensive Survivorship Program: Getting Started

by Mary S. McCabe, RN, MA

Since the publication of the Institute of Medicine report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, in 2005, much attention has been focused on the needs of cancer survivors. This consciousness raising has been an essential first step to improving the quality of care for survivors. Still, the most important efforts lie ahead; specifically, there needs to be a national effort to design, implement, and evaluate programs and services that can become part of routine follow-up care.

The Association of Community Cancer Centers (ACCC) has set a wonderful example for all of us who care for cancer patients by taking some of these first steps: first, challenging us to make survivorship a formal component of the continuum of care and second, by publishing a variety of models in *Oncology Issues* to serve as examples of what can be achieved. But let's take a step back from viewing programs that already exist and review how survivorship care is provided today and the essential elements to consider in setting up services and programs for the future.

## Getting Started

Today, there are more than 12 million cancer survivors in the United States. We know that post treatment follow-up care is routinely occurring as a matter of practice. However, we also know that the duration of this follow-up care and its associated services varies across the country. Most often follow-up visits, however timed, are focused on surveillance for recurrence, and communication with other healthcare providers about the prior treatment and the plan of care is woefully lacking. What is needed is the development and application of a follow-up plan that is comprehensive yet practical so it can be provided in the community where the majority of cancer care in the United States occurs. Based on the fact that survivors face lifetime health risks that are dependent on the cancer, treatment exposures, genetic predispositions, comorbid health conditions, and lifestyle behaviors, such a plan should include at a minimum:

- Surveillance for recurrence of the primary cancer
- Cancer screening for new cancers using national guidelines
- Identification and management of the physical and psychological effects of cancer and its treatment
- Health promotion recommendations
- Provision of a treatment summary and follow-up care plan (see Figure 1).

Since most busy oncology programs have very limited time and resources for education and counseling, this plan of care need not be provided solely by the oncology team. Rather, a number of models of care can be considered where different providers and organizations take responsibility for various services. For example, the general medical follow-up care components can be “shared” with the primary care provider (a model that is used successfully for other chronic diseases). This type of provider is uniquely suited to manage the health promotion counseling and recommendations for cancer screening. In addition, information about the community organizations offering counseling and other forms of psychosocial support can be provided as part of the package of survivorship care through the development of simple resource lists. This flexible, “shared-care” approach is very important in figuring out how to deliver high-quality survivorship care. What matters most is that there is a plan of care and that, just like with an orchestra, there is a score to be followed, someone in charge, with each independent group working in concert.

What is needed now is action. We must begin to expect good communication between oncologists and primary care providers using the care plan as the communication tool. Acknowledging the expertise of the other providers for important issues such as anxiety, depression, and sexual dysfunction will assure they are addressed by those more expert than the oncology team. As for psychosocial services, remember that you don't have to build it or own it to use it. Most communities have excellent resources for smoking cessation, physical rehabilitation, nutrition counseling, and support groups. Aggressively refer to these organizations and/or partner with them to have survivor-focused programs.

We have a growing body of information about the medical, psychosocial and economic issues facing survivors; we have recommendations from national groups about the importance of addressing this period of oncology care; and we have examples of care models from other disease groups that are effective in providing quality services. So, despite health system barriers and our still evolving knowledge base, it is critically important to get started. Most importantly, our survivors deserve it.

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## Figure I. Memorial Sloan-Kettering Cancer Center Summary of Cancer Treatment and Follow-up Plan

Date of Preparation: \_\_\_\_\_

Name:

Cancer Diagnosis:

Date of Diagnosis:

Date Completed Therapy:

Relapse:

### Cancer Treatment

Surgery

Surgeon/Phone:

Date

Procedure

Pathology

Radiation Therapy

Radiation Oncologist/phone:

Dates

Type

Field

Dose (cGy)

Chemotherapy/Biotherapy

Medical Oncologist/Phone:

Regimen #1:

Regimen #2:

Drug Name

Significant Cumulative Doses  
(units or mg/m<sup>2</sup>)

### Follow-up Plan

Visit Schedule

Testing

Screening Recommendations:

Colonoscopy

Prostate specific antigen (PSA)

Mammogram

Other

Nurse Practitioner: